

The challenge of communication during home mechanical ventilation

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- I. Laakso K, Hartelius L & Idvall M (2009). Ventilator-supported communication – a case study of patient and staff experiences. *Journal of Medical Speech-Language Pathology*, 17(4):153-164.
- II. Laakso K, Markström A, & Hartelius L (2009). Communication and quality of life in individuals receiving home mechanical ventilation. *International Journal of Therapy and Rehabilitation*, 16(12):648-655.
- III. Laakso, K., Markström, A., Havstam, C., Idvall, M., & Hartelius, L. The communication experience of individuals treated with home mechanical ventilation. (Accepted for publication in the *International Journal of Language & Communication Disorders*).
- IV. Laakso, K., Markström, A., Havstam, C., Idvall, M., & Hartelius, L. Communicating with individuals receiving home mechanical ventilation, the experiences of key communication partners. (Submitted for publication).



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ABSTRACT

The overall aim of this thesis was to explore and describe experience of communication during home mechanical ventilation (HMV) in adults, thereby contributing to increased knowledge and awareness of issues related to ventilator-supported communication. Mechanical ventilatory support seriously affects speaking and communication. Earlier studies have shown that many ventilator-supported patients experience difficulty and frustration with their speech and voice production.

A mixed-method research approach guided the research design of the thesis, which includes four studies. Study I was a qualitative case study exploring experience of communication of both an intensive care unit nurse and an individual receiving HMV. Participants in Studies II-IV were recruited from the National Respiratory Centre (NRC) and comprised 19 individuals receiving HMV, as well as their key communication partners (CPs). Study II included analyses of the following quantitatively measured variables; speech intelligibility, health-related quality of life and communicative participation. Studies III-IV were qualitative interview studies, exploring the experience of communication of both individuals receiving HMV and their key CPs.

One of the main findings in the first study was that ventilator-supported communication was perceived as time consuming, strenuous and requiring training. The second, larger study investigated individuals who are treated with HMV and revealed low average intelligibility scores and an impact on both HRQL and communicative participation. However, these aspects did not appear to be closely correlated. The third study concluded that individuals receiving HMV experience a long and lonely struggle to find a voice and lack support from health professionals. Six subthemes detailed different facets of their experience: *Managing changed speech conditions*, *Prioritising voice*, *A third party supporting communication*, *Using communication to get things done*, *Depending on technology* and *Facing ignorance*. The fourth and final study found that CPs encounter a number of communication limitations in the ventilator-supported individual's speech and communication, such as a weak voice and interrupted speech flow. CPs used different functional communication strategies to improve communication and assumed the role of a communication facilitator. CPs also described insecurity managing these roles, which evoked emotional reactions, but they also showed an ability to grow with experience.

In overall terms, the findings characterise aspects of communication during HMV, including the challenges facing both the individuals receiving HMC and their CPs. The findings revealed that communicative issues were a major concern for individuals receiving HMV and that CPs played an important role in communicative success. Further, it was concluded that there is a lack of knowledge about issues related to communication during HMV, from the point of view of ventilator-supported individuals, communication partners and health care professionals. It is to be hoped that the findings from the studies can be applied to raise awareness and create training programmes relating to the skills and competence needed to be an effective CP and to optimise the communication of individuals receiving HMV.

Key words: Communication, communicative partner, health-related quality of life, home mechanical ventilation, International Classification of Functioning, Disability and Health, qualitative research design.